Improving the Care of Children with Mental Illness: A Challenge for Public Health and the Federal Government

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To appreciate the crisis in community mental health care in the United States, consider the impact on children:

- 14,000 youth were incarcerated unnecessarily in the first six months of 2004 because community mental health treatment was not available.[1] One jail administrator in Louisiana described the problem as "warehousing youths with mental illnesses due to lack of mental health services."[1]
- 12,700 youth were steered over to the child welfare or juvenile justice systems by their parents in order to obtain mental health care.[2] This 2001 count by the General Accounting Office, covered just 19 states and 30 counties.
- One-third of children in urgent need of psychiatric admission were stuck in medical beds.[3] One recent study of a major Massachusetts emergency department found that the most severely ill were the least likely to receive appropriate placement.
- Hundreds of children are locked in psychiatric facilities for thousands of days after they have been cleared to leave, simply because other, less restrictive settings of care are unavailable.[4] One child was stuck in a hospital for nearly a year.

Individually, each case is a tragedy for a child, his or her family, and the community. Taken together, these examples reflect a broken system in which many youth with severe mental illness are everywhere except where they should be: living in their communities and receiving intensive and effective mental health services.

Traditionally, responsibility for mental health services has been divided among an array of agencies. Some children receive care in state-funded clinics and hospitals, others come to the attention of education agencies, still others land in the foster care system, and many eventually end up in jail. But to respond to the present crisis, the nation needs a coordinated response that is not limited by these bureaucratic divisions.

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It is a challenge uniquely suited for public health.

Four core efforts by public health officials could form the basis for establishing a system that provides all youth with timely and effective community mental health services:

- Ensuring access to treatment,
- Promoting coordination of services,
- Encouraging research, and
- Monitoring progress.

In each area, new initiatives by the federal government would make an enormous difference in supporting the activities of dedicated state and local officials.

ACCESS TO TREATMENT

According to the U.S. Public Health Service, a core function of public health is "assuring the quality, accessibility, and accountability of medical care."[6] Unfortunately, this assurance is lacking for children's mental health in communities across the country. At a hearing of the Senate Governmental Affairs Committee in July 2004, experts testified that the inadequacy of community mental health services is the root cause of the current crisis.[7] Only about one in five youth with significant mental illness receives any treatment, and there are major racial and ethnic disparities in access to care.[8] Once inside the mental health care system, many families of youth with severe behavioral problems and emotional disorders struggle to obtain the treatment they need. Delays and backlogs undermine care for all children, regardless of race, class, or insurance status.

Through outreach, case management, and monitoring, state and local public health agencies should ensure that every child has access to care. For such an effort to be possible, however, services must be physically and financially available in the first place. The federal government must support a major expansion in treatment infrastructure and insurance programs.

The program with the greatest influence over children's mental health care is Medicaid, which insures about one-quarter of all U.S. children and is the largest funder of psychiatric care for children in the country.[9] Recently, state budget cuts, low reimbursement rates, and local coverage decisions have all undermined Medicaid's promise of access to care.[10] But with such a large role in the system, and as such an important partnership between the federal and state governments, Medicaid must be reinvigorated for this crisis to be resolved.

Federal leaders at the Center for Medicare & Medicaid Services (CMS) should start by identifying community-based treatment approaches that have been proven to work for high-risk youth. One approach for consideration is multi-systemic therapy, in which a diverse and highly trained team of caregivers modifies treatment and therapy for the family based on the day-to-day condition of the child.[11] Studies have shown this program to reduce out-of-home placement, criminal behavior, substance abuse, school failure, and other serious behavioral problems in teens with serious mental and emotional disorders.[12,13] Other promising approaches include functional family therapy, targeted case management, and therapeutic foster care.[8]

Few of these innovative services are currently accessible to children enrolled in state Medicaid programs.[14] Adhering to the legal requirement that state Medicaid programs must cover effective treatments for children, CMS should act to ensure that their availability is the rule, not the exception. Some state programs will need technical assistance in publicizing this coverage and updating their billing systems to accommodate new team-based strategies. Others may need prodding from the federal government.

As Medicaid expands its provision of effective community mental health services, Congress and the Administration should also extend Medicaid to include more children at risk and to provide more comprehensive care. CMS should strongly encourage state Medicaid programs to utilize an approach created in 1982, known as the Katie Beckett option. In November 1981, President Reagan was moved by the story of a three-year-old girl who was institutionalized in Iowa. Her parents wanted to care for her at home, but complex rules of income eligibility deemed the child poor in an institution but not poor in her own home.[15] The Department of Health and Human Services, and later Congress, responded by permitting states to provide intensive community services to children with mental and physical disabilities who would otherwise be institutionalized, even if their family incomes are too high to be covered under normal Medicaid rules. Yet nearly 25 years later, the promise of this option is largely unfulfilled. Currently, only about 10 states have used the Katie Beckett option to provide mental health services.[16]

CMS should also encourage and provide technical assistance to states to use home- and community-based waivers for children with serious mental disorders. These waivers permit expansions of the types of services covered by traditional Medicaid to keep youth from being institutionalized. Under current law, these waivers can be used to prevent children from requiring psychiatric hospitalization, but only a few states do so.[16] In addition, Congress should make a technical

legislative correction so that the waivers can also be a tool to keep children from requiring expensive residential treatment.

For uninsured children and children with inadequate public or private health insurance who still cannot get the care they need, Congress should pass bipartisan legislation, called the Family Opportunity Act, which would allow families to purchase Medicaid coverage for their severely ill children.

COORDINATION OF EFFORTS

Public health is responsible for "leading the development of sound health policy and planning."[6] In the case of children's mental health policy, planning is desperately needed. Parents of children with mental illness frequently report difficulty accessing necessary services—even when they might be available.[17] Children in the child welfare system can languish in foster care, those in the juvenile justice system can be stalled in detention, and those followed primarily by the educational system can be stuck in an unstable classroom poorly suited for learning. The key to progress is to link these systems together with effective community-based mental health treatment.

One state that has attempted to create such an integrated mental health system is New Mexico. According to testimony at a Governmental Affairs Committee hearing in July 2004, Governor Bill Richardson pushed key state agencies to implement a plan to improve mental health services. The largest state juvenile detention center added an outpatient mental health center on site, the parole board collaborated with health care providers to provide immediate referrals to treatment, and the police set up a system to bring youth for immediate mental health screening and placement, rather than to jail.[18]

The reported results have been dramatic. Over several years, the number of incarcerated youth dropped by half, saving millions of dollars.[18] The state has also realized savings by shifting costs from fully state-funded juvenile justice services into the Medicaid program, which is a federal/state match. Reinvesting these savings, the state shifted 40 full-time jobs from the juvenile justice system directly into intensive community mental health treatment.[18]

Federal funding can be an excellent incentive to promote this type of collaboration. Currently, the Substance Abuse and Mental Health Services Administration provides grants under the Child Mental Health Services Act to cities, counties, and states. These grants require recipients to create a "system of care" for children with severe mental illness involving key agencies, health care providers, and private partners. So far, approximately 100 cities, counties, and states have obtained these grants with a total federal expenditure of $106 million in fiscal year 2005. Despite evidence demonstrating effectiveness and substantial need across the country, the vast majority of communities do not receive this federal support. This program should be significantly expanded.

Congress should also directly encourage collaboration at the state level. The Keeping Families Together Act, another bipartisan proposal, would provide grants only to states that ensure access to individualized treatment and family support services across a range of state agencies. These states would then be prohibited from forcing families to relinquish custody of their children to obtain needed care.

RESEARCH

A key role of public health is "researching to develop new insights and innovative solutions."[6] Public health agencies should cooperate with researchers seeking new avenues to prevent severe mental illness and treat troubled children in their communities.

At the federal level, the National Institutes of Health (NIH) funds a range of grants on children's mental health. Many of these grants focus on the assessment and treatment of specific high-risk populations, such as runaway youth, juvenile offenders, and children experimenting with alcohol and controlled substances. These efforts could be enhanced by the development of a broad and well funded national strategy, crossing NIH institutes, to develop innovative approaches to children's mental health. Part of this strategy should focus on evaluating practical interventions that could be readily adopted by Medicaid and other insurers. Such an approach could lead to major progress for youth with severe mental illness, their families, and their communities.

MONITORING

The political reality of children's mental health care is that momentum for reform can fade quickly. Pressure for Medicaid reform can give way to budget cutting. Collaboration between state agencies can turn into finger pointing. One mechanism of keeping pressure for change on local and state governments is the regular, public release of data on how many children are in the wrong place without the right treatment. Such monitoring is a core function of public health.[6]

The federal government should promote this process by delineating what represents inappropriate

treatment of children. States should not detain youth waiting for services or force parents to relinquish custody simply to obtain care. These standards should be built into relevant areas of federal law, such as core protections for youth under the Justice and Delinquency Prevention Act.

To expose these poor outcomes, the federal government should annually survey states on custody relinquishment and juvenile detention facilities on inappropriate incarceration. Local and state data should be made available to public health agencies. Yet despite a recent recommendation for such monitoring by the Government Accountability Office, the Department of Health and Human Services and the Justice Department have resisted.[19,20] Their argument has been that further study of the problem is not necessary, since everyone knows a problem exists.

This perspective misunderstands the purpose of monitoring. As in many areas of public health, the reporting of data is not just for academic discussion. It is a tool to allow parents, mental health advocates, and the news media to hold political leaders accountable for gaping holes in mental health care for children.

And the monitoring itself makes its own statement. Counting these children, who are so often forgotten, sends the clear message that these children count.

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